

***Submission to the Standing Committee on Human
Resources, Skills and Social Development and the
Status of Persons with Disabilities Study of Bill C-44,
Helping Families in Need***

Prepared by

The Canadian Association for Community Living

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On behalf of the Canadian Association for Community Living, I want to thank you for the invitation to participate in the Committee study of Bill C-44. My name is Tyler Hnatuk and I am Policy and Programs Officer with the Canadian Association for Community Living.

The Canadian Association for Community Living (CACL) is a family-based association that assists people with intellectual disabilities and their families to lead the way in advancing inclusion in their communities. CACL was founded in 1958 by parents of children with disabilities who wanted supports and services in their home communities instead of institutions. Since that time CACL has grown into a federation of 13 provincial and territorial associations comprising over 300 local associations and more than 40,000 members.

Our association has in the past called for changes to the *Canada Labour Code*, *Employment Insurance Act*, *Canada Pension Plan* and *Income Tax Act* in order to recognize the support and care that family members provide to a child with a disability. Over the past decade we have participated in community consultations, coalitions and policy reform processes aimed at recognizing the challenges and disproportionate financial impacts faced by families of children with disabilities.

I would like to say from the outset that we are encouraged by the direction of Bill C-44 and its proposal to recognize the challenges faced by families in these extraordinary circumstances. By recognizing the situations of parents of a child who has been a victim of a crime, is missing, or is critically ill or injured, this proposed Bill recognizes the extraordinary caregiving

responsibilities some families face, and the impact on their labour force attachment.

As such we wholeheartedly support the direction of this Bill and the window of support and flexibility that it provides to parents in terribly difficult circumstances.

When compassionate care provisions were first introduced to Employment Insurance, we joined others in calling for enhancement of these measures to recognize the extraordinary caregiving situation that parents of children with severe disabilities face. We continue to be of the view that recognition is needed for families of children with severe disabilities and we have developed detailed proposals with respect to an overall strategy for addressing the disproportionate caregiving situation that these families are in, of which changes to the *Canada Labour Code*, *Employment Insurance Act*, *Canada Pension Plan* and *Income Tax Act* are one modest but important piece.

In this brief submission I will provide a profile of parents of children with disabilities through analysis of national data sets and other Canadian research, look to the current policy context in Canada for support for caregivers of children with disabilities and draw on the lived experience of families who are a part of our movement in order to outline the challenges that families face today.

I want to begin by sketching the statistical profile of families of children with disabilities in Canada. We know that children with disabilities and their families endure greater and disproportionate rates of poverty and low-income than others in Canada. Data from the Participation and Activity Limitation Survey (or PALS) from 2006 indicates that children with disabilities are more likely to live

in households that fall below the Low Income Cut Off than children who do not have a disability.¹ It should be pointed out that the LICO does not take into account the non-reimbursed costs related to disability. Therefore, the low-income situation of children with disabilities and their families is likely understated.

When considering employment, we know that parents' ability to maintain a career is significantly affected by having a child with a disability. PALS 2006 found that parents of children with disabilities report that as a result of their child's condition 38% worked fewer hours, 37% changed their work hours, 26% did not take a job, 22% quit work, and 20% did not take a promotion. The employment situation of mothers is most affected with 64% of mothers being most affected and 8% of fathers most affected.²

Help Needed with Everyday Activities

One of the major disability-related supports people require throughout their lives is help with everyday activities. Of children with disabilities whose parents require help, nearly 26% have parents who received help, but needed more. About 40% have parents who received no help, but needed some. Of the many parents needing additional help, nearly three quarters cite cost as the primary reason that they cannot get it and more than a third of parents report having out of pocket expenses for getting the assistance that they need.³ The bulk of disability-related support for everyday activities is provided by family members. This includes help with personal care, health care, household work,

¹ Statistics Canada, Participation and Activity Limitation Survey 2006 : Families of Children with Disabilities in Canada. Ottawa: Statistics Canada, 2010.

² Statistics Canada, Participation and Activity Limitation Survey 2006 : Families of Children with Disabilities in Canada. Ottawa: Statistics Canada, 2010.

³ Statistics Canada, Participation and Activity Limitation Survey 2006 : Families of Children with Disabilities in Canada. Ottawa: Statistics Canada, 2010.

and transportation and includes matters such as personal advocacy, planning, coordination and brokering of needed services, emotional support, communication assistance and financial expenditures for disability-related, expenses, and so on.

Parents also report barriers and difficulties in coordinating medical care with nearly one in five parents of children with disabilities reporting difficulties, and of these parents most cited lack of time (63.1%) and work conflicts (60.2%) as the main reasons for difficulty in coordinating this care.

But I would like to illustrate these facts and figures with just a few of the stories that we hear from thousands of parents of children with intellectual disabilities throughout the county. We hear regularly from families who are struggling to make ends meet as the sole result of their decision to push for what they believe is best for their child. Driven by a vision for inclusion and a good life, families are increasingly being pushed into hardship and desperation—in many cases to the brink...

Consider a plea received this month from a Saskatchewan mother of a young son with a disability. They are a single income family on what would otherwise be a modest income. But they are below the poverty line and have filed for bankruptcy. This mother was recently advised that she should “put her child in care”—a course of action that she has no intention to follow.

Or consider the numerous stories that have appeared in print and television media over the past months of parents who have “dropped off” their adult children with community support agencies, because they can no longer fulfill the duties of caregiving.

Or consider the plea of an Ontario mother who recently spoke at a provincial hearing on government services and whose voice resonated with families across the country as she detailed the fifteen years that their family has spent on waiting lists for support, and the two hours per week of support that allow her adult son to have shower once in a while.

These families and thousands of others across the country have spent their lifetimes providing billions of dollars worth of what would otherwise be paid care for their children with significant needs.

The UN Committee on the Rights of the Child recently reviewed Canada's 3rd and 4th reports to the Committee and concluded with observations that Canada must:

“ensure that children with disabilities, and their families, are provided with all necessary support and services in order to ensure that financial constraints are not an obstacle in accessing services and that household incomes and parental employment are not negatively affected.”⁴

We believe that it is quite clear that for families of children with severe disabilities, the activities of caregiving reach far beyond the typical duties of parenthood.

As I mentioned earlier, CACL has developed detailed and more comprehensive proposals that could provide recognition for these extraordinary circumstances. In the context of a broader strategy, extension of Employment Insurance benefits could form one small

⁴ UN Committee on the Convention of the Rights of Children with Disabilities, *Concluding Observations*, October 6, 2012. Accessible at: http://www2.ohchr.org/english/bodies/crc/docs/co/CRC-C-CAN-CO-3-4_en.pdf

but critical contribution toward mitigating the current financial impacts related to raising a child with significant needs.

As we know well from research, early intervention can be critical in shaping outcomes later in life. These interventions might be related to medical procedures, intensive therapies, educational activities, and so on. Or the interventions may be less formal added demands of parenting that relate to doing the “inclusion work” in the context of communities and systems where parents of children with disabilities still encounter so many doors slammed shut in generic services, programs and supports. If parenting is a fulltime job, the “inclusion work” of parents of children with disabilities is far above and beyond what can be expected to be regular caregiving responsibilities.

The significant work undertaken by parents of children with severe disabilities to better their communities and build better lives for their sons and daughters needs to be recognized as the extraordinary task that it is. An extension of EI benefits to parents of children with severe disabilities may seem a small window in the context of the overwhelming need for support. But these forms of recognition are critical and as we can see, the consequences of missing these small windows of opportunity can be significant—as we see with the finding that 40% of kids in the child welfare system have disabilities, and as we see with the media stories of parents dropping off their children with community agencies.

While we recognize what a small window something like employment insurance benefits may seem in the context of such great need, it is with these modest amounts of support that parents of children with disabilities can do so much. It would

further mark a tremendous step forward toward recognizing the contributions of family caregivers of children with disabilities.

We urge the Committee to recognize that some families face extraordinary caregiving responsibilities that have a direct impact on labour force attachment, career development and family well-being. We believe that this should be the focus for the purposes of the EI system. It is not so much the source or cause of extraordinary responsibilities and challenges that is the policy issue, but the fact that some families in this country, through no fault of their own, face extraordinary challenges which have a direct impact on parents' labour force participation. It is the labour force *impact* of those challenges that should be the focus.

I would like to thank the Committee for the opportunity to appear, and would be pleased to address any questions or comments you may have.